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PRINCIPLES FOR GOOD PRACTICE

BY

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WASHINGTON, D.C.
JANUARY 24, 1983

(GREETINGS TO HOSTS, GUESTS)

IT IS A GREAT HONOR FOR ME TO JOIN YOU THIS MORNING TO DELIVER THE KEYNOTE ADDRESS FOR THIS 7TH CLINICAL CONGRESS. I AM AWARE OF THE OUTSTANDING CLINICIANS WHO HAVE PRECEDED ME AT THIS PODIUM -- DRS. DUDRICK AND NESTLE AND DARBY, TO NAME ONLY THREE. AND I AM ALSO DEEPLY IN YOUR DEBT FOR ARRANGING A REUNION FOR ME WITH SEVERAL DISTINGUISHED LEADERS IN THE FIELD OF PARENTERAL AND ENTERAL NUTRITION: DR. JONATHAN RHOADS, YOUR PRESIDENT-ELECT DR. EZRA STEIGER, DR. JAMES MULLEN, AND DR. HARRY VARS.

I ALSO WANT TO EXTEND A HAND OF SYMPATHY TO ALL OF YOU WHO ARE <u>NOT</u> FROM PHILADELPHIA BUT WHO ARE NEVERTHELESS DOING GOOD THINGS IN THIS FIELD. IT MUST BE VERY DIFFICULT FOR YOU. BUT I WILL CONFESS TO YOU THAT NOTHING WOULD MAKE ME HAPPIER THAN TO KNOW THAT, IN NOT MANY YEARS FROM NOW, THERE MIGHT VERY WELL BE A LARGE AND FAMOUS BOSTON CONTINGENT AND ANOTHER ONE FROM HOUSTON AND ONE FROM NEW ORLEANS AND YET ANOTHER FROM LOS ANGELES. I THINK THAT NOTHING WOULD PLEASE US PHILADELPHIANS MORE THAN THAT KIND OF COMPETITION.

DR. STEFFEE TOLD ME I COULD SPEAK ON ANY ASPECT OF CLINICAL NUTRITION, NUTRITION EDUCATION, NUTRITIONAL TECHNOLOGIES, OR ANY OTHER SUBJECT APPROPRIATE TO THIS MEETING AND HIGH ON MY OWN AGENDA.

EXPERIENCE ALSO SUGGESTS THAT MEMBERS OF AN A.S.P.E.N. CONGRESS ARE GRACIOUS LISTENERS. WITH THAT AS A CUE, I WILL TAKE SOME LIBERTIES THIS MORNING TO SPEAK OF THOSE PARTICULAR CONCERNS THAT, IN MY OPINION, FORM THE VITAL LINKS BETWEEN THE TWO KEY WORDS IN THE THEME OF THIS YEAR'S CONGRESS: "PRINCIPLES" AND "PRACTICE."

MY OWN EXPERIENCE IN THIS FIELD HAS MADE ME PARTICULARLY SENSITIVE TO THE DIFFERENCE BETWEEN A PRINCIPLE OF NUTRITION THERAPY -- WHAT WE MAY FEEL WE OUGHT TO DO, ON THE BASIS OF OUR BEST SCIENTIFIC INFORMATION -- AND THE REALITY OF APPLYING THAT PRINCIPLE -- ACTUALLY DOING WHAT WE BELIEVE NEEDS TO BE DONE. THIS WAS THE DILEMMA THAT FACED A NUMBER OF US IN THE MID-1940s, TOWARD THE END OF WORLD WAR II, WHEN SO MUCH OF THE PIONEERING WORK IN PARENTERAL AND ENTERAL NUTRITION WAS BEING ACCOMPLISHED.

I WAS A HARRISON FELLOW IN GENERAL SURGERY AND RESEARCH SURGERY AT THE TIME AT THE HOSPITAL OF THE UNIVERSITY OF PENNSYLVANIA AND WORKING TOWARD MY DEGREE OF DOCTOR OF SCIENCE FROM THE GRADUATE SCHOOL OF MEDICINE. I HAD THE PRIVILEGE OF PARTICIPATING IN SOME OF THE BASIC RESEARCH FROM WHICH HAVE SINCE COME SO MANY OF THE REMARKABLE, LIFE-SAVING DEVELOPMENTS IN PARENTERAL NUTRITION IN RECENT YEARS. MY COLLEAGUES -- DR. JONATHAN RHOADS, CECILIA RIEGLE, AND HARRY VARS --

AND I PUBLISHED A NUMBER OF PAPERS ON THE NUTRITIONAL REQUIREMENTS OF PRE-OP AND POST-OP PATIENTS. OF PARTICULAR INTEREST TO US AT THE TIME WAS THE PROBLEM OF NITROGEN BALANCE. ONE OF THE THINGS WE TRIED TO DO FOR OUR PATIENTS WAS TO HELP THEM BUILD UP A VERY POSITIVE NITROGEN BALANCE IN THE FEW DAYS BEFORE SURGERY SO THAT THEY COULD SUSTAIN A STRONG POST-OPERATIVE NEGATIVE NITROGEN BALANCE.

BUT THERE WERE FEW CHOICES IN AMINO ACIDS AVAILABLE FOR OUR USE. IN ADDITION, WE WERE USING SOME EXPERIMENTAL MECHANICAL MATERIALS PRODUCED BY DR. OLAF S. RASK IN THE BIOCHEMISTRY DEPARTMENT AT JOHNS HOPKINS. HOWEVER, THE COMMERCIALLY AVAILABLE AMINO ACID SOLUTIONS AND THE EXPERIMENTAL MATERIAL FROM HOPKINS PRODUCED ADVERSE REACTIONS IN ALMOST ALL PATIENTS, PARTICULARLY WHEN WE PUSHED TO GET THOSE HIGHER PARENTERAL LEVELS OF NITROGEN INTAKE AMONG OUR PRE-OPERATIVE PATIENTS. THE MOST DISTRESSING OF THESE REACTIONS WAS A SEVERE FLUSHING WHICH WAS VERY UNCOMFORTABLE FOR MOST PATIENTS.

THE MATERIALS WE USED -- THE NEEDLES, FOR EXAMPLE, THAT WERE PLACED IN THE VEINS FOR INFUSION OVER A LONG PERIOD OF TIME -- THESE THINGS OFTEN PRODUCED THROMBOSES, ALSO. I SOMETIMES LOOK BACK AND WONDER AT HOW MUCH WE COULD HAVE ACCOMPLISHED IN OUR NUTRITIONAL RESEARCH, IF WE ONLY HAD HAD THE MATERIALS SO COPIOUSLY AVAILABLE TODAY...PARTICULARLY TODAY'S FLEXIBLE, INNOCUOUS, AND VERSATILE TEFLON OR SILASTIC TUBING.

ONE OF THE WAYS THAT I CHOSE TO TRY TO DELIVER HIGH-PROTEIN PARENTERAL NUTRITION WAS TO THREAD SOME KIND OF CONDUIT THROUGH THE FEMORAL VEIN AND UP INTO THE ABDOMINAL VENA CAVA. AN OBVIOUS CHOICE FOR A CONDUIT WOULD BE A URETERAL CATHETER. BUT IN THOSE DAYS, URETERAL CATHETERS WERE MADE OF WOVEN SILK. THEY WERE NOT STERILIZED IN AN AUTOCLAVE BUT RATHER WERE SOAKED IN A SOLUTION OF GREAT PROMISE AND SLIGHT EFFECT. IN ADDITION, THE SILK CATHETER ITSELF -- WHETHER STERILIZED OR NOT -- IRRITATED THE ENDOTHELIUM OF THE VEIN AND, HENCE, IT TOO PRODUCED THROMBOSES.

ON SEVERAL OCCASIONS, FRUSTRATED BY THE ABSENCE OF THE PROPER TUBING, I EVEN WENT DOWN TO ARCH STREET IN PHILADELPHIA. ARCH STREET WAS THEN KNOWN AS "RADIO ROW" BECAUSE IT HAD A NUMBER OF LITTLE SUPPLY SHOPS THAT CATERED TO PEOPLE WHO BUILT THEIR OWN RADIOS. IT WAS 1945 AND THE BIG MANUFACTURERS WERE JUST BEGINNING TO SWITCH FROM WARTIME PRODUCTION TO PEACETIME CONSUMER PRODUCTION. TELEVISION WAS STILL A FEW YEARS OFF, SO HOME RADIO ASSEMBLY WAS FAIRLY COMMON. I WOULD BROWSE AMONG THESE LITTLE STORES AND COME AWAY WITH COPPER RADIO WIRE CARRIED IN A SHELLACKED SHEATH. THE WIRE WAS AVAILABLE IN A VARIETY OF COLORS, BY THE WAY, TO HELP THE HOME HANDYMAN KEEP THEM STRAIGHT. I DON'T RECALL ANY WHITE WIRE BUT I DO RECALL BUYING A LOT OF BEIGES AND LIGHT YELLOWS.

I WOULD TEASE THE COPPER WIRE OUT OF THE SHEATH, WHICH THEN BECAME A THIN, FLEXIBLE CONDUIT THROUGH WHICH I MIGHT DELIVER THE NECESSARY I.V. FLUIDS. I DID HAVE SOME SUCCESS WITH THIS APPROACH. HOWEVER, THE SLEEVE OF SHELLAC WAS ALSO IRRITATING TO THE INTIMA OF THE BLOOD VESSEL. EVENTUALLY WE HAD TO ABANDON THIS RATHER NOVEL APPROACH AFTER ONE ELDERLY PATIENT SUFFERED A COMPLETE THROMBOSIS OF THE VENA CAVA, CLEARLY CAUSED BY THE EX-RADIO WIRE.

BUT OUR SEARCH DID NOT END. IN FACT, I MIGHT BE THE FIRST PERSON TO HAVE USED A POLYETHYLENE TUBE FOR INTRAVENOUS FEEDING. I HAD COME UPON THE MATERIAL COMPLETELY BY CHANCE DURING A VISIT TO DARTMOUTH COLLEGE, MY ALMA MATER, AND THE PHYSIOLOGY LAB OF DR. ROY P. FORSTER. DR. FORSTER HAD BEEN TESTING DIFFERENT KINDS OF WHAT HE CALLED "SPAGHETTI TUBING" FOR THE PARENTERAL DELIVERY OF NUTRIENTS INTO SMALL LABORATORY ANIMALS. JUST PRIOR TO MY VISIT, DR. FORSTER HAD OBTAINED SOME NEW TUBING FROM A PERSON IN NEW JERSEY WHO WAS EXPERIMENTING WITH POLYETHYLENE AND AN EXTRUDER.

I WAS FASCINATED AT THE PROPERTIES AND POSSIBILITIES OF THE POLY-ETHYLENE TUBING AND TOOK SOME BACK WITH ME TO PHILADELPHIA. I BEGAN TO EXPERIMENT WITH IT AS AN I.V. CONDUIT AMONG PATIENTS REQUIRING PAREN-TERAL NUTRITION AT THE HOSPITAL OF THE UNIVERSITY OF PENNSYLVANIA AND AT THE CHILDREN'S HOSPITAL OF PHILADELPHIA.

BUT NOT LONG AFTER MY INITIAL EXPERIMENTS WITH THIS NEW MATERIAL, I WAS APPOINTED A FELLOW IN PEDIATRIC SURGERY AT BOSTON CHILDREN'S HOSPITAL. I JOURNEYED TO BOSTON IN APRIL OF 1946, LEAVING BEHIND FOR THE TIME BEING MY KEEN INTEREST IN THE FURTHER DEVELOPMENT OF THE POLYETHYLENE TUBE FOR PARENTERAL USES. THE MANUFACTURER OF THAT TUBING WAS INITIALLY DISCOURAGED BY MY DEPARTURE, BUT WE REMAINED IN TOUCH AND HE SOON INTERESTED SEVERAL NEUROSURGEONS AT BOSTON CHILDREN'S HOSPITAL IN USING HIS NEW MATERIAL IN THEIR OWN HIGHLY SENSITIVE WORK.

I HAVE ALWAYS BEEN PROUD OF MY OWN MODEST ROLE AS SOMETHING OF A CATALYST IN BRINGING TOGETHER THE PEOPLE AND THE PROCEDURES THAT LED TO THE DEVELOPMENT OF THE FIRST COMPANY IN THE UNITED STATES TO MANUFACTURE SAFE, FLEXIBLE, AND VERSATILE POLYETHYLENE TUBING FOR INTRAVENOUS FEEDING.

FOR MANY YEARS, PHYSICIANS HAD REALIZED THE NEED TO IMPROVE THE METHODS OF DELIVERY OF PARENTERAL AND ENTERAL NUTRITION. THE PRINCIPLES OF PARENTERAL AND ENTERAL NUTRITION HAD BEEN KNOWN AND ACCEPTED FOR DECADES AND, IN SOME INTERPRETATIONS, KNOWN FOR CENTURIES. BUT THERE WAS NO TECHNOLOGY AND NO GUIDANCE TO TRANSLATE

THOSE ACCEPTED PRINCIPLES INTO ACCEPTED MEDICAL PRACTICE. WHEN THE LINKAGE WAS FINALLY MADE, IT WAS MADE PARTLY THROUGH THE TRADITIONAL SCIENTIFIC METHOD, ORDERLY AND ORGANIZED, AND PARTLY THROUGH SERENDIPITY.

I HAVE ALWAYS BEEN PARTIAL TO THE STATEMENT BY THE GREAT LIFE SCIENTIST, DR. ALBERT SZENT-GYORGI, THAT "A DISCOVERY IS AN ACCIDENT MEETING A PREPARED MIND." CERTAINLY THAT NOTION RATHER SUCCINCTLY DESCRIBES A GREAT DEAL OF WHAT HAS OCCURRED IN THE FIELD OF PARENTERAL AND ENTERAL NUTRITION. AND I MUST SAY THAT, IN DR. RHOADS AND DR. VARS AND DR. DUDRICK AND MANY OTHERS, THIS FIELD HAS BEEN BLESSED WITH SOME OF THE MOST EXCEPTIONAL OF THE PREPARED MINDS IN MEDICINE.

BUT I MUST ADD THAT THE CHALLENGE OF PUTTING PRINCIPLES INTO PRACTICE IS NOT EXCLUSIVELY TECHNOLOGICAL IN NATURE, AS YOU WELL KNOW. THERE ARE OTHER ISSUES AND CONSIDERATIONS THAT COME INTO PLAY. MANY OF THEM COME TO MIND WHEN I RECALL AGAIN THE CIRCUMSTANCES SURROUNDING THE HANDLING OF THE INFANT KELEEN BURGESS, BACK IN 1967.

I SHOULD BEGIN BY NOTING THAT BEFORE 1967 THE NEONATAL SURGEON IN PARTICULAR HAD GREAT DIFFICULTY DELIVERING THE NECESSARY LIFE-SAVING NUTRITION TO PATIENTS WHO HAD BEEN BORN WITH RUPTURED OMPHALOCELES OR

GASTROSCHISIS. AS YOU KNOW, "FROSTING" MAY OCCUR ON THE BOWEL, AS A RESULT OF EXPOSURE TO AMNIOTIC FLUID. FOLLOWING BIRTH, A CERTAIN PERIOD OF TIME MUST ELAPSE FOR THIS FROSTING TO BE RESORBED. WHILE THAT IS TAKING PLACE, IT IS NOT POSSIBLE TO PROVIDE THE NEWBORN PATIENT WITH VITAL ENTERAL NUTRITION.

TWENTY YEARS AGO, THERE WASN'T MUCH YOU COULD DO ABOUT IT, AND WE WOULD LOSE MANY PATIENTS THROUGH INANITION. TODAY, OF COURSE, THE CORRECTIVE SURGERY IS MUCH SIMPLER AND THE PATIENT CAN BE PLACED ON T.P.N. TO RECEIVE ALL THE ESSENTIAL NUTRITION DURING RECOVERY AND WHILE THE BOWEL IS GRADUALLY ASSUMING ITS NORMAL, POST-NATAL FUNCTIONS. WE LEARNED A GREAT DEAL ABOUT THIS TECHNOLOGY WITH THE HELP OF LITTLE KELEEN BURGESS AND HER FAMILY.

KELEEN BURGESS WAS BORN IN 1967 AND TRANSFERRED SOON AFTER TO THE CHILDREN'S HOSPITAL OF PHILADELPHIA, WHERE I HAD BEEN SURGEON-IN-CHIEF FOR 19 YEARS AND WOULD BE FOR ANOTHER 14. KELEEN WAS BORN WITH GANGRENE OF THE BOWEL JUST BELOW THE LIGAMENT OF TRIETZ TO JUST ABOVE THE ILEOCECAL VALVE. ONE OF MY COLLEAGUES HAD RESECTED ALL THE DAMAGED BOWEL AND CREATED AN ANASTOMATIC LINK BETWEEN THE TWO REMAINING VIABLE ENDS. BUT HER LIFE WAS STILL IN JEOPARDY.

AN OBVIOUS SOLUTION WOULD HAVE BEEN A BOWEL TRANSPLANT. HOWEVER, SUCH A PROCEDURE WAS NOT FEASIBLE THEN AND IT IS STILL NOT FEASIBLE. SO WE HAD TO TURN TO THE ONLY ALTERNATIVE LEFT TO US: TOTAL PARENTERAL NUTRITION, OR T.P.N.

UNTIL THAT TIME, YOU WILL REMEMBER, WE HAD ONLY LIMITED EXPERIENCE WITH THIS CONCEPT. THE FEW SUCCESS STORIES -- AND THEY WERE QUITE RECENT...1965 AND 1966 -- ALL CONCERNED SEVERAL BEAGLE PUPPIES THAT HAD BEEN FED INTRAVENOUSLY FOR A YEAR OR MORE BY OUR COLLEAGUES AT THE HARRISON DEPARTMENT OF SURGICAL RESEARCH AT THE UNIVERSITY OF PENNSYLVANIA. UP TO THAT TIME THERE HAD BEEN NO HUMAN EXPERIMENTATION INVOLVING THE T.P.N. CONCEPT.

WITH THE PERMISSION OF HER PARENTS, WE PROCEEDED WITH THIS CONCEPT. MR. AND MRS. BURGESS DESERVE A GREAT DEAL OF CREDIT FOR GIVING THEIR CONSENT, KNOWING HOW LIMITED OUR EXPERIENCE WAS WITH LONG-TERM PARENTERAL NUTRITION. BUT THEY DID GIVE IT AND WE WENT AHEAD. AND CREDIT MUST ALSO GO TO THE PHYSICIANS ON THIS HISTORIC CASE, DR. DOUGLAS W. WILMORE AND DR. STANLEY J. DUDRICK, WHO WORKED WITH MY COLLEAGUE, DR. HARRY BISHOP, ON THE DAY-TO-DAY MANAGEMENT OF THE BURGESS CHILD.

KELEEN BURGESS WAS ON INTRAVENOUS T.P.N. FOR HER FIRST 45 DAYS OF LIFE AND, OVER THE NEXT 22 MONTHS, WAS NOURISHED MAINLY BY INTRAVENOUS HYPERALIMENTATION BEFORE SHE ULTIMATELY SUCCUMBED TO SEPSIS. THERE IS A PLAQUE IN THE ATRIUM OF THE CHILDREN'S HOSPITAL OF PHILADELPHIA THAT MEMORIALIZES HER EXTRAORDINARY CONTRIBUTION TO OUR KNOWLEDGE OF LONG-TERM PARENTERAL CARE OF ADULTS AS WELL AS CHILDREN. AND THIS YEAR, THE CHILDREN'S HOSPITAL WILL INAUGURATE ITS NEW HONORARY LECTURESHIP NAMED FOR KELEEN BURGESS. DURING HER BRIEF TWO YEARS OF LIFE, KELEEN PROVED A WHOLE RANGE OF HYPOTHESES THAT WERE TO BENEFIT THOUSANDS UPON THOUSANDS OF LIVES THEREAFTER.

LITTLE KELEEN BURGESS IS ONE OF A LINE OF PATIENTS WHO HAVE BEEN HEROES AND HEROINES OF MEDICINE. AMONG THE EARLIEST IN THIS COUNTRY, OF COURSE, WAS ALEXIS ST. MARTIN, FROM WHOSE STOMACH DR. WILLIAM BEAUMONT DREW SO MUCH NEW INFORMATION. THE LATEST OF THEM, IN MY OPINION, IS DR. BARNEY CLARK, THE FIRST HUMAN TO LIVE WITH AN ARTIFICIAL HEART. LIKE CLARK, KELEEN -- OR, MORE PRECISELY, KELEEN'S PARENTS -- HAD VIRTUALLY NO CHOICE. THE ALTERNATIVE TO THE REGIMEN OF T.P.N. WAS AN EARLY DEATH. AND WHILE KELEEN DID SURVIVE FOR NEARLY TWO YEARS, EACH HOUR AND EACH DAY OF THOSE TWO YEARS WAS A NEW EXPERIENCE AND YIELDED NEW INFORMATION...HARD DATA...THE FACTS THAT NO ONE HAD HAD BEFORE THEN.

KELEEN DID THRIVE AND GROW DURING THAT PERIOD. IN MOST RESPECTS SHE WAS A HEALTHY, GROWING CHILD. BUT HER ABILITY TO DO THAT WAS, IN EFFECT, AN ABILITY THAT WAS OUT AHEAD OF OUR LEVEL OF SCIENTIFIC KNOWLEDGE. WE DID NOT KNOW HOW TO DEAL WITH ALL THE CONSEQUENCES OF THIS KIND OF LIFE. AND, IN FACT, ONE OF THE CONSEQUENCES -- INFECTION -- WAS BEYOND OUR ABILITY TO CONTROL AND KELEEN BURGESS WAS LOST TO HER FAMILY AND TO MEDICINE.

AS OF TODAY, DR. CLARK IS NOT AT SUCH RISK. HIS PROGNOSIS SEEMS TO BE BETTER AND HIS LEVEL OF CARE IS MUCH HIGHER TODAY THAN IT WOULD HAVE BEEN, HAD HE BEEN GIVEN AN ARTIFICIAL ORGAN OF ANY KIND BACK IN THE LATE 60s. AND I CERTAINLY HOPE THAT THE PARALLELS BETWEEN KELEEN BURGESS AND BARNEY CLARK STOP RIGHT THERE. YET, EVEN WITH BARNEY CLARK, WE ARE LEARNING NEW THINGS EACH DAY -- THINGS FOR WHICH WE HAVE LITTLE EXPERIENCE AND NO CLEAR PLAN. AND THERE ARE VERY FEW CERTAINTIES.

I KNOW THAT A GREAT MANY OF YOU HAVE PATIENTS ON HOME T.P.N. AND, AS A SUBSET WITHIN MEDICINE, ENTERAL AND PARENTERAL NUTRITION HAS INDEED MADE EXTRAORDINARY TECHNOLOGICAL PROGRESS, THANKS TO THE

EFFORTS OF MEMBERS OF THIS SOCIETY AND YOUR COLLEAGUES. BUT I WOULD SUBMIT -- AND I WOULD HOPE YOU WOULD AGREE -- THAT THERE IS STILL A GREAT DEAL YET TO LEARN CONCERNING THE OUT-PATIENT OR HOME-CARE APPLICATION OF THE T.P.N. CONCEPT:

§ WE ARE AWARE, FOR EXAMPLE, OF THE POSSIBILITIES OF GREAT VARIATIONS IN METABOLIC CHANGE FROM PATIENT TO PATIENT AND, WITHIN EACH PATIENT, FROM DAY TO DAY. BUT MUCH IS YET TO BE LEARNED AND UNDERSTOOD ABOUT THESE CHANGES.

§ WE ALSO KNOW THAT HOME T.P.N. IS NOT A TOTAL LIBERATION FOR THE PATIENT. IT DOES REQUIRE CERTAIN ADJUSTMENTS IN BEHAVIOR. SOME MIGHT EVEN SAY IT REQUIRES AN EXCHANGE OF ONE SET OF RESTRICTIVE BEHAVIORS FOR ANOTHER SET OF EQUALLY RESTRICTIVE BEHAVIORS. WE HAVE MUCH WORK AHEAD OF US, I BELIEVE, BEFORE WE CAN BE COMFORTABLE WITH OUR UNDERSTANDING OF THE BIOBEHAVIORAL ASPECTS OF HOME T.P.N.

§ AND WE ALSO NEED TO FOCUS MORE ATTENTION ON THE KIND OF IMPACT THE HOME T.P.N. REGIMEN HAS UPON THE PATIENT'S FAMILY. WE ALL KNOW FROM OUR OWN LIVES THAT A GENEROSITY OF SPIRIT MAY NOT, BY ITSELF, ALWAYS BE ENOUGH TO HANDLE PROFOUND CHANGES IN FAMILY RELATIONSHIPS.

WE MAY NEED GUIDANCE, HELP, SUPPORT, UNDERSTANDING...AND THAT MUST COME FROM INDIVIDUALS WHO WOULD BE WORKING FROM A BROAD AND FIRM KNOWLEDGE BASE. I WOULD IMAGINE THAT EVEN THIS AUDIENCE WOULD AGREE THAT WE HAVE QUITE A DISTANCE TO GO BEFORE WE CAN FEEL TRULY SECURE WITH THE BODY OF KNOWLEDGE AVAILABLE TO US.

WHILE THINKING ABOUT THESE QUESTIONS AND PREPARING FOR THIS MEETING, I EXPERIENCED SOMETHING OF A SENSE OF DÉJA VU. JUST A FEW WEEKS AGO I WELCOMED A NUMBER OF COLLEAGUES TO A "SURGEON GENERAL'S CONFERENCE ON HANDICAPPED CHILDREN AND THEIR FAMILIES." ONE FOCUS OF THIS CONFERENCE WAS THE NEED FOR MOVING MORE RESPIRATOR-DEPENDENT CHILDREN FROM THE HOSPITAL TO THEIR OWN HOME SETTINGS. AND I HEARD MANY STATEMENTS OF PRINCIPLE AND CITATIONS OF PRACTICE THAT I AM SURE, WITH ONLY SMALL CHANGES, WOULD APPLY EQUALLY TO THE CONCERNS OF THIS AUDIENCE THIS MORNING. FOR EXAMPLE, AMONG THE PRINCIPLES WHICH WE WOULD ACCEPT MIGHT BE THESE HALF-DOZEN:

° THE TECHNOLOGY FOR THE HOME CARE OF THE PATIENT MUST REPRESENT A CONSIDERABLE COST SAVING OVER INPATIENT CARE, WITH NO LOSS OF EFFECTIVENESS. IN OTHER WORDS, WE MUST NOT BE READY TO COMPROMISE THE EFFECTIVENESS OF MEDICAL CARE IN THE NAME OF ECONOMY. THAT IS A TRAP THAT CAN BE FATAL BOTH TO OUR PATIENTS AND TO THE PRACTICE OF GOOD MEDICINE.

° THE TECHNOLOGY FOR HOME CARE MUST, INDEED, BE DESIGNED FOR INCORPORATION INTO THE NORMAL OR AVERAGE HOME ENVIRONMENT. WE MUST GUARD AGAINST THE REVERSE TAKING PLACE. PUBLIC POLICY PLANNERS HAVE BEEN CRITICIZED IN THE PAST FOR HAVING "MEDICALIZED" A NUMBER OF LARGER SOCIAL ISSUES: TEENAGE PREGNANCIES, SUBSTANCE ABUSE, VIOLENT CRIME, AND SO ON. YET, OF POSSIBLY GREATER SERIOUSNESS WOULD BE ANY ATTEMPT TO "MEDICALIZE" THE HOME ENVIRONMENT. THE GOAL OF TECHNOLOGY, THEREFORE, OUGHT NOT TO BE THE TRANSFER OF THE HOSPITAL GESTALT TO THE FAMILY HEARTH, BUT RATHER TO MAINTAIN THE WARMTH AND CHARACTER OF THAT HEARTH AGAINST DIFFICULT ODDS.

° A THIRD -- AND RELATED -- PRINCIPLE SHOULD REST UPON OUR RECOGNITION THAT THE HOME IN WHICH HEALTH CARE IS TAKING PLACE CANNOT BE AN ISLAND WITHIN THE COMMUNITY. IT MUST BE NOURISHED BY THE COMMUNITY AND ACCEPTED AS NORMAL. THAT MAY SOUND PECULIAR, BUT I AM SURE THAT MOST OF US KNOW OR HAVE HEARD OF UNFORTUNATE INSTANCES IN WHICH COMMUNITIES OR NEIGHBORHOODS HAVE OBJECTED TO THE PRESENCE OF RESIDENTS WHO WERE SOMEHOW "DIFFERENT," PEOPLE WHO WERE DISABLED OR NOT FULLY COMPETENT. THOSE OF US WHO LOOK TOWARD THE GREAT POTENTIAL OF HOME HEALTH CARE HAD BETTER BEGIN NOW TO STRENGTHEN THE BACKBONE OF MANY OF OUR COMMUNITIES, TO HELP GIVE THEM THE RESOLVE AND THE DECENCY THAT IS NO DOUBT THERE, BUT MAY BE ONLY LATENT.

° WE MUST ALSO DO WHATEVER WE CAN TO ENSURE ADEQUATE, AVAILABLE, AND ACCESSIBLE HEALTH AND SOCIAL SERVICES FOR THE PATIENT AND THE FAMILY. I THINK WE MAY SOMETIMES STIMULATE TECHNOLOGY IN SUCH A WAY THAT IT RACES AHEAD OF THE ABILITY OF THE COMMUNITY TO ABSORB IT AND INTELLIGENTLY SUPPORT IT. I KNOW OF NO INSTANCE IN WHICH HOME HEALTH CARE MIGHT BE PRESCRIBED BUT WHICH WOULD NOT ALSO REQUIRE THE ASSISTANCE OF SOME SUPPORTIVE HEALTH OR SOCIAL SERVICE AGENCY FROM THE COMMUNITY. I THINK HOME HEALTH CARE AND COMMUNITY SERVICES GO HAND-IN-HAND. OF COURSE, THE MEMBERS OF THIS SOCIETY -- PARTICULARLY THOSE WITH PATIENTS ON HOME T.P.N. -- ARE A GOOD DEAL MORE KNOWLEDGEABLE ABOUT THIS THAN I. AND I SUSPECT THAT YOU WOULD JOIN ME IN BEING CATEGORICALLY EXPLICIT ABOUT THE NEED FOR GOOD COMMUNITY SUPPORT SERVICES TO BE IN PLACE FOR OUR HOME-CARE PATIENTS.

° I WOULD ALSO SUGGEST THAT WE PUT INTO PLACE WHATEVER ADMINISTRATIVE ARRANGEMENTS MIGHT BE NECESSARY TO GUARANTEE SOME LEVEL OF CONTINUED, RESPONSIBLE CONTACT BETWEEN THE DISCHARGING INSTITUTION AND THE PATIENT AT HOME. THERE WOULD SEEM TO BE TWO REASONS FOR THIS:

* THE <u>FIRST</u> IS THE SIMPLE REASON THAT WE MUST NOT ALLOW TECHNOLOGY AND AN ACCEPTING FAMILY TO UNWITTINGLY "ORPHAN" OUR PATIENTS FROM THE MEDICAL CARE SYSTEM. I DON'T BELIEVE THAT THE

MAINTENANCE OF THE SYSTEM'S CONCERN AND RESPONSIBILITY HAS TO BE AN EXPENSIVE, BUREAUCRATIC TANGLE OF PAPERWORK, ALTHOUGH I IMAGINE THE LESS TALENTED AMONG US MIGHT MAKE IT SO.

* MY SECOND REASON, HOWEVER, IS PURELY SELFISH AND IT GOES BACK TO OUR EXPERIENCE WITH KELEEN BURGESS. EACH HUMAN BEING IS DIFFERENT...AND SPECIAL. YET, THE LIFE EXPERIENCES OF EACH ONE CAN ALSO TELL US THINGS THAT ARE OFTEN VERY USEFUL IN THE TREATMENT AND CARE OF SOMEONE ELSE. THEREFORE, WE NEED TO STAY IN TOUCH WITH OUR T.P.N. PATIENTS AT HOME BECAUSE THEIR LIVES ARE THE BEST TEXTBOOKS FOR THE HISTORY OF TOTAL PARENTERAL NUTRITION. I SAID IT WAS A SELFISH REASON AND I MAKE NO APOLOGIES FOR IT.

° MY LAST POINT THIS MORNING -- AND A PRINCIPLE THAT HAS SHONE THROUGH THE LIVES OF ALL THE MEN AND WOMEN WHO HAVE BEEN LEADERS IN THIS FIELD OF PARENTERAL AND ENTERAL NUTRITION -- IS THE PRINCIPLE THAT ALL EVENTS IN A PERSON'S LIFE ARE CONNECTED. A MOMENT AGO, I USED THE IMAGE OF A "TEXTBOOK," BUT THAT IS NOT THE BEST METAPHOR TO EMPLOY. MUCH MORE PREFERABLE IS THE IMAGE OF A SCROLL, SOMETHING LIKE THOSE MARVELOUS ORIENTAL SCROLLS THAT TELL STORIES OF HEROIC DEEDS AND GENTEEL ROMANCE, IN WHICH ONE PICTURE GROWS OUT OF THE ONE BEFORE AND LEADS THE EYE QUITE NATURALLY TO THE NEXT IMAGE TO COME.

THE DELIVERY OF NUTRITION IS ONE OF A NUMBER OF INTERCONNECTING IMAGES. IT IS REPEATED BECAUSE IT IS BASIC TO THE MAINTENANCE OF LIFE -- BUT IT IS NOT LIFE ITSELF. EVERY EVENT IN LIFE OCCURS WITHIN THE CONTEXT OF EVENTS THAT HAVE COME BEFORE AND THOSE THAT ARE YET TO COME. THIS IS WHAT IS SO SPECIAL ABOUT THE KELEEN BURGESSES AND THE BARNEY CLARKS AMONG OUR PATIENTS. FOR THEM, NUTRITION AND THE LIFE PROCESSES DO GO ON, BUT WE BARELY UNDERSTAND HOW THEY CONNECT, AND WE RACE TO KEEP UP, TO BE SENSITIVE TO THE ENTIRE CONTEXT OF A PATIENT'S LIFE.

I THINK THAT REALIZATION CAME TO EVERYONE WHO ATTENDED KELEEN. AS LITTLE AS WE KNEW ABOUT T.P.N. AT THE TIME, IT WAS MUCH MORE THAN WE KNEW ABOUT THE BURGESS FAMILY OR ABOUT KELEEN HERSELF. THE CHILD NEVER ASSUMED THE FULL DIMENSIONALITY OF A HUMAN BEING AND SO WE NEVER REALLY GOT TO KNOW HER IN ANY TERMS OTHER THAN THOSE ASSOCIATED WITH HER BASIC NEEDS AND VITAL SIGNS.

TO THIS DAY, I BELIEVE WE DID THE RIGHT THING FOR KELEEN AND SHE AND HER FAMILY MORE THAN REPAID US BY THE WEALTH OF KNOWLEDGE WE DREW FROM HER EXPERIENCE. BUT WE MUST NEVER LOSE SIGHT OF THE FACT THAT THE DELIVERY OF NUTRITION -- BY ITSELF -- MAY NOT BE ENOUGH...A PATIENT MAY WANT AND NEED MORE. AND THE REALLY DIFFICULT DECISIONS -- THE TRUE

TEST OF OUR REAL-WORLD PRACTICES -- WILL COME AS WE DEAL WITH THIS PRINCIPLE OF MEDICAL CARE, ONE THAT IS AS OLD AS THE HIPPOCRATIC OATH ITSELF.

I AM INDEED VERY PLEASED TO BE AMONG YOU THIS MORNING AND TO MAKE SOME SMALL CONTRIBUTION TO A FIELD THAT HAS HELD MY INTEREST FOR CLOSE TO FOUR DECADES. I ENCOURAGE YOU TO CONTINUE ADVANCING THE SCIENCE AND TECHNOLOGY OF PARENTERAL AND ENTERAL NUTRITION AT MEETINGS SUCH AS THIS, IN YOUR OWN LABORATORIES AND CLINICS, AND ELSEWHERE IN YOUR PERSONAL AND PROFESSIONAL LIVES. AS YOU DO SO, PERHAPS YOU MIGHT WISH TO RECALL NOW AND THEN A LITTLE SENTENCE THAT I FIND ESPECIALLY WELL-STATED. THEY ARE THE WORDS OF MISS FLANNERY O'CONNOR, ONE OF OUR GREAT AMERICAN WRITERS. WHILE SHE SPEAKS TO HER OWN CRAFT, I'VE OFTEN WISHED THAT A CLINICIAN HAD SAID IT INSTEAD, SINCE IT IS SO PERTINENT TO OUR WORK AS WELL. MISS O'CONNOR SAID, "THE WRITER DOES NOT SOLVE MYSTERIES BUT ACCEPTS MYSTERY AND SEEKS TO UNDERSTAND IT IN A LIFE."

THANK YOU.

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